DOCUMENT RESUME

ED 151 996 EC 103 754

TITLE Science and Technology in the Service of the Physically Handicapped. Summary.
INSTITUTION National Academy of Sciences - National Research Council, Washington, D.C. Div. of Medical Sciences.
PUB DATE 76
NOTE 30p.

EDRS PRICE MF-$0.83 HC-$2.06 Plus Postage.
DESCRIPTORS Aurally Handicapped; Government Role; *Needs Assessment; *Physically Handicapped; *Rehabilitation; *Research Needs; *Sciences; Services; Speech Handicapped; State of the Art Reviews; *Technology; Visually Handicapped

ABSTRACT

The report of the Committee on National Needs for the Rehabilitation of the Physically Handicapped focuses on the current problems in the field, the areas in which additional knowledge is needed, and directions in which the society and government should move both with respect to the acquisition of new knowledge and a more effective organization of effort. Listed among recommendations is that for major areas of disability, a comprehensive national overview should be developed outlining in full its demography, national cost, and related social and organizational structure. Rehabilitation is discussed in terms of the medical and social framework, demography, organizations and programs, the policy picture, and economics. A section on the state of the art in science and technology and their application covers research and development, blindness and low vision, hearing and speech, manipulation and locomotion, and basic neuroscience and rehabilitation. The tables of contents for volumes 1 and 2 of the full report are also included. (SBH)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

ED151996

U.S. DEPARTMENT OF HEALTH,
EDUCATION & WELFARE
NATIONAL INSTITUTE OF
EDUCATION

THIS DOCUMENT HAS BEEN REPRODUCED EXACTLY AS RECEIVED FROM THE PERSON OR ORGANIZATION ORIGINATING IT. POINTS OF VIEW OR OPINIONS STATED DO NOT NECESSARILY REPRESENT OFFICIAL NATIONAL INSTITUTE OF EDUCATION POSITION OR POLICY

SCIENCE AND TECHNOLOGY IN THE SERVICE OF THE PHYSICALLY HANDICAPPED

SUMMARY

Committee on National Needs for the Rehabilitation of the Physically Handicapped

Division of Medical Sciences

Assembly of Life Sciences

National Research Council

National Academy of Sciences

Washington, D. C. 1976

EC 103754

NOTICE

The project that is the subject of this report was approved by the Governing Board of the National Research Council, whose members are drawn from the Councils of the National Academy of Sciences, the National Academy of Engineering, and the Institute of Medicine. The members of the Committee responsible for the report were chosen for their special competences and with regard for appropriate balance.

This report has been reviewed by a group other than the authors according to procedures approved by a Report Review Committee consisting of members of the National Academy of Sciences, the National Academy of Engineering, and the Institute of Medicine.

NATIONAL ACADEMY OF SCIENCES

OFFICE OF THE PRESIDENT
2101 CONSTITUTION AVENUE
WASHINGTON, D. C. 20418

November 8, 1976

The Honorable David Mathews
Secretary of Health, Education,
and Welfare
330 Independence Avenue, S.W.
Washington, D. C. 20201

and

The Honorable Richard L. Roudebush
Administrator of Veterans Affairs
Veterans Administration
810 Vermont Avenue, N.W.
Washington, D. C. 20420

Gentlemen:

I am pleased to transmit herewith the report, "Science and Technology in the Service of the Physically Handicapped."

The concern of the National Academy of Sciences for the needs of the disabled and handicapped members of our society has deep roots, reaching back to World War II when the Academy undertook a program to improve the quality and availability of prosthetic and orthotic devices for military amputees. Ever since, the Academy and its National Research Council have had a significant and continuing role in the development, evaluation and utilization of new devices to assist the disabled and in the education and training of individuals to serve their needs. This has been made possible by financial support from the wartime Office of Scientific Research and Development, and later from the Army, the Veterans Administration and agencies of the Department of Health, Education, and Welfare. The nation is deeply indebted to the many scientists, clinicians and engineers who, as members and associates of the National Research Council Committee on Prosthetics Research and Development and its predecessor groups, gave generously of their time and knowledge to advance our ability to be helpful to the physically handicapped.

The Academy's involvement with the physically handicapped began with concern for the specific problems of veterans and later expanded to consideration of assistance to all physically disabled persons. Attention was long focussed on the design and utilization of diverse prosthetic appliances and devices, taking advantage of the knowledge and skills to be found in the scientific and engineering communities, then expanded to concern for the entire array of technical, clinical, educational, psychological and social services that should be made available to assist physically handicapped persons to lead useful and productive lives and have reasonable opportunity to compete in our society. It was recognition of this expanded set of considerations that led to the appointment in April 1975 of the Committee on National Needs for the Rehabilitation of the Physically Handicapped.

The committee was requested to examine broadly what needs to be done to improve the utilization of science and technology in restoring physically handicapped individuals to more active roles in society. This report makes it evident that while we can take some measure of pride in what has been accomplished, much, much more remains to be done. It is my hope that this report of our study of these problems will be useful to you and to others who bear responsibility for assisting our handicapped fellows. It is my further hope that this Academy will be privileged to assist in meeting the goals here set forth.

Finally, may I take this opportunity publicly to convey to Professor Rosenblith and his committee our deepest appreciation.

Sincerely yours,

Philip Handler
President

Enclosure

PREFACE

Physical handicaps sharply reduce our nation's human resources and add considerably to human suffering and to our society's economic burden. Estimates of the number of persons in the United States who are physically handicapped vary considerably depending upon the definition and severity of the handicap. Given the difficulties of obtaining a reliable estimate, one must be aware that these numbers vary all the way from 6 to 28 million* persons, with the greatest uncertainty at both ends of the age spectrum.

Some recent estimates by the Social Security Administration place the number of physically disabled individuals who are limited in work activities around eight million. In addition, an estimated seven and one-half million are unable to work at all. Millions more, either too young or too old to work, are limited in their daily activities. Estimates of the financial burden of physical disability in the United States are thus, understandably, unreliable and crude. Figures ranging from several billions of dollars to several tens of billions can be found in the literature, providing little basis for an estimate that would stand up to criticism. In addition to the burden borne by the handicapped and their families, this financial burden is borne by federal and state programs, of which there are many (more than 103 federal programs are listed by the Office for Handicapped Individuals).

The data available indicate that this burden is increasing if only because the number of aged is increasing and because the number of chronically ill and severely injured persons surviving continues to increase because of advances in medical care. Added to the loss in productivity are the personal losses suffered by the physically handicapped from limitations imposed on their ability to participate in many aspects of life--losses that cannot be measured in dollars.

Only a very small fraction of the country's scientific and technological capabilities have been effectively utilized to aid the physically handicapped. Few devices commonly used by the handicapped show the influence of current technology at all; many devices such as wheelchairs, which are produced by a multimillion-dollar industry, have been virtually unchanged for decades. Compared to the costs of rehabilitation and compensation for physical handicaps, only a minute fraction goes to research and development concerned directly with the needs of the handicapped.

*The Swedish Institute for the Handicapped estimates that in Sweden in 1975-1976, more than 1 million of the 8 million inhabitants were handicapped (data from Birger Roos, Technical Director, Handikappinstitutet, August 24, 1976). Approximately 12% of the Swedish population are considered handicapped, a figure in good agreement with the higher estimate above for the United States.

The National Academy of Sciences-National Research Council, aware that with the aid of science and technology within an appropriate institutional and societal setting large numbers of handicapped individuals might be restored to more productive and normal lives, established the Committee on National Needs for the Rehabilitation of the Physically Handicapped in April 1975. The Committee was to examine broadly what needs to be done to improve the utilization of science and technology in restoring physically handicapped individuals to more active roles in society. The prevalence of chronic conditions is necessarily greater in the adult and especially the aged segments of the population than in the young; but the Committee is also acutely sensitive to the special needs of children, especially the congenitally handicapped. It is estimated that about 3 percent of all schoolage children are significantly handicapped. Many of these children require special assistance in acquiring skills they have never had. Thus they require habilitation for essential functions, rather than rehabilitation. For this report, however, the needs of the handicapped population were considered as a whole. Little attempt was made to consider the multiply handicapped separately or to analyze the components of the population by age or by cause of the handicapping condition. Further, because of limited time and resources, the Committee decided to limit the state of the art review to blindness and low vision, hearing and speech problems, and difficulties with manipulation and locomotion.

The charge to the Committee was (a) to assess the nation's needs regarding the application of science and technology to aid the physically handicapped, (b) to formulate specific plans of action to meet those needs, and (c) to specify how the NAS-NRC might best help meet the nation's needs in this area.

The Committee first met in April 1975 to receive its charge and to plan its work. An intensive workshop, on the needs and problems of the handicapped was held in Woods Hole, Massachusetts from June 21 through July 1, 1975. The work of the Committee is detailed in the Appendix.

Volume 1 comprises the Committee's report. Volume 2 contains six papers on social science and policy in areas essential to the evaluation of the needs of the handicapped but not represented by the Committee membership. These papers were contributed by consultants at the request of the Committee.

The objective of the Committee's report is to indicate the current problems in the field, to highlight the areas in which we need additional knowledge, and to point out directions in which our society and our government should move, both with respect to the acquisition of new knowledge and with respect to a more effective organization of effort.

COMMITTEE ON NATIONAL NEEDS FOR THE REHABILITATION

OF THE PHYSICALLY HANDICAPPED

WALTER A. ROSENBLITH, Ing. Radio. and Ing. Radioelect., Chairman; Provost, Massachusetts Institute of Technology, Cambridge, Massachusetts

EDWARD V. EVARTS, M.D., Chief, Laboratory of Neurophysiology, National Institute of Mental Health, National Institutes of Health, Bethesda, Maryland

JOSEPH GOODGOLD, M.D., Director of Research and Training, Department of Rehabilitation Medicine, New York University Medical Center, New York, New York

LEON D. HARMON, Professor of Biomedical Engineering, Department of Biomedical Engineering, Case Western Reserve University, Cleveland, Ohio

STEPHEN C. JACOBSEN, Ph.D., Director, Projects and Design Laboratory, Department of Mechanical Engineering, University of Utah, Salt Lake City, Utah

ROBERT W. MANN, Sc.D., Whitaker Professor of Biomedical Engineering, Massachusetts Institute of Technology, Cambridge, Massachusetts

JAMES D. MILLER, Ph.D., Coordinator of Special Projects, and Head, Comparative Psychoacoustics, Central Institute for the Deaf, St. Louis, Missouri

JACQUELIN PERRY, M.D., Chief, Kinesiology, Rancho Los Amigos Hospital, Downey, California

ALAN A. REICH, Deputy Assistant Secretary for Educational and Cultural Affairs, Department of State, Washington, D.C.*

ALAIN B. ROSSIER, M.D., Professor of Spinal Cord Rehabilitation, Harvard Medical School, and Chief, Spinal Cord Inury Service, Veterans Administration Hospital, Boston, Massachusetts

ARAN SAFIR, M.D., Director, Institute of Computer Science, Mt. Sinai School of Medicine, New York, New York

Staff

ELENA O. NIGHTINGALE, M.D., Ph.D., Senior Staff Officer, Division of Medical Sciences, Assembly of Life Sciences, National Research Council

Consultants

MONROE BERKOWITZ, Ph.D., Professor of Economics, and Director of the Disability and Health Economics Research Section, Rutgers University, The State University of New Jersey, New Brunswick, New Jersey

CHARLES C. EDWARDS, M.D., Senior Vice President for Research and Scientific Affairs, Becton, Dickinson and Company, Rutherford, New Jersey

KENNETH A. KLIVINGTON, Ph.D., Program Associate to Program Officer, and Administrator Basic Research Program, Alfred P. Sloan Foundation, New York, New York**

ROBERT MORRIS, D.S.W., Kirstein Professor of Social Planning, and Director, Levinson Policy Institute, The Florence Heller Graduate School for Advanced Studies in Social Welfare, Brandeis University, Waltham, Massachusetts

JOHN H. NOBLE, JR., Ph.D., Director of Research and Policy Analysis for Social Services/Human Development, Office of the Assistant Secretary for Planning and Evaluation, Department of Health, Education, and Welfare, Washington, D.C.

ALBERT T. PIMENTEL, Assistant to the President for Public Service, Gallaudet College, Washington, D.C.

The work of the Committee was supported by the Rehabilitation Services Administration (Contract No. HEW-105-76-4103), by the Veterans Administration (Contract No. V101(134) P-243), and by a grant from The Arthur Vining Davis Foundations.

* Alan A. Reich served on the Committee until April 1976, and did not participate in the formulation of the recommendations.

**Kenneth A. Klivington, Ph.D., served as Staff Officer to the Committee from January 1975 to January 1976.

CONTENTS

PREFACE v

I. FINDINGS AND RECOMMENDATIONS 1

II. REHABILITATION IN OUR SOCIETY 5

Medical and Social Framework 5

Demography 6

Organizations and Programs 6

The Policy Picture 7

Economics of Rehabilitation 8

III. STATE OF THE ART: SCIENCE AND TECHNOLOGY AND THEIR APPLICATION 9

Research and Development 9

Blindness and Low Vision 10

Hearing and Speech 12

Manipulation and Locomotion 14

Basic Neuroscience and Rehabilitation 16

CONTENTS OF VOLUME 1 OF THE FULL REPORT 17

CONTENTS OF VOLUME 2 OF THE FULL REPORT 19

I. FINDINGS AND RECOMMENDATIONS

The difficulties inherent in bringing the research and development capability of the United States to bear upon the diverse needs of the physically handicapped are highlighted in this report.

Although medical specialties related to rehabilitation have their own associations, there is presently no body of specialists that, together with concerned and informed consumers, has a sufficiently common perception of the problems of the handicapped to be able to suggest common action and priorities. The several departments and agencies of the federal government (or even bureaus and offices of a single department) and the numerous private (or voluntary) agencies are so special-purpose in character as to make it difficult for them to cooperate in a cohesive fashion.

Thus, a multiprofessional mechanism of sufficient quality and visibility is urgently required to assist both the public and private sectors in formulating a strategy that is effective in providing the needed devices and services for the physically handicapped and in aggregating resources and markets to this end.

The Committee, therefore, makes the following recommendations.

1. A Board should be established at the earliest possible time within the framework of the National Research Council (most likely within the Division of Medical Sciences of the Assembly of Life Sciences) in cooperation with the several relevant NRC assemblies and commissions as well as in cooperation with the Institute of Medicine.

This Board should have several functions:

- It should provide a focus for the creation of a community of all the disciplines and groups working with the physically disabled and those concerned with their rehabilitation.
- It should monitor ongoing research and its extension into useful development.
- Soon after its inception, it should study the federal agencies involved with rehabilitation in order to determine the best location for housing of each kind of rehabilitation research.
- It should provide a forum in which the "lead agency" of the federal government (if and when one is selected) could obtain a critical review of its planning and operating procedures.

- It should--in conjunction with the relevant government agencies--establish a coherent and realistic research and development agenda, aid in the establishment of priorities, and serve as a source of advice in the establishment of appropriate peer review panels. It should also systematically review research and development policies and see to it that services and devices are adequately evaluated.

- It should ensure that relevant information is appropriately disseminated and that the physically handicapped are given adequate opportunity (for instance, in specially designed workshops) to examine progress in the field, together with specialists having the requisite technical competence.

- Its national advisory function should include conferences and publications to disseminate (throughout the research community) those basic and applied questions that are central to the restoration of function to the handicapped.

- It should establish programs with other countries for cooperation in rehabilitation research and to share experiences and information so that each nation can benefit by utilizing what is appropriate for its handicapped.

The Committee envisions a Board composed of about two dozen members, of which approximately two-thirds might be identified as specialists in the various disciplines and professions that relate to the physically handicapped and to their rehabilitation. It is expected that roughly one-third of the Board membership be drawn from appropriate representatives of the public interest and from various consumer groups. Thus, it is expected that persons from the following fields would be members of the Board:

Professionals

- Relevant specialties of medicine, such as neurology, ophthalmology, orthopedics, otolaryngology, and rehabilitation medicine; and of engineering, such as electrical, mechanical, biomaterials, and control engineering

- Allied health professions

- Pertinent biomedical sciences, such as neurosciences and fields that relate to disorders of communication and locomotion

- Social and behavioral sciences.

Representatives of the Public Interest

Consumers

- Associations that group the handicapped or disabled
- Industrial and labor organizations concerned with problems of rehabilitation

Liaison should be maintained with such government agencies as the Rehabilitation Services Administration, the Veterans Administration, the Social Security Administration, the Departments of Labor, Defense, Commerce, Transportation and Housing and Urban Development, and professional organizations concerned with the handicapped.

The present research and development effort in the service of the physically handicapped is highly fragmented throughout the federal government and even within the Department of Health, Education, and Welfare (DHEW), a condition that does not lend itself to the development of the required technical competence in the several pertinent fields. The Rehabilitation Services Administration has attempted to take a leadership role, in spite of its highly inadequate resources.

2. It is recommended that the Secretary of DHEW ask the Assistant Secretary for Administration and Management in consultation with the assistant secretaries of Health and of Human Development to determine which organizational arrangement would lead to the necessary strengthening of research and development functions (including a mechanism of peer review) on behalf of the physically handicapped. That arrangement needs to be sensitive to the obligations of service to the handicapped and also needs to be capable of interacting effectively with related efforts in the Veterans Administration, the Social Security Administration, the Departments of Labor, Defense, Commerce, Transportation, Housing and Urban Development; and the various state programs.

3. For major areas of disability a comprehensive national overview should be developed, outlining in full its demography, national cost, and related social and organizational structure.

The collection of demographic data might be coordinated by the National Center for Health Statistics in consultation with the Social Security Administration.

The introduction of technological advances to aid the handicapped usually requires a continuing effort that initially may be close to basic

research and that progressively (in a gradual or stepwise fashion) moves to the stage of practical utilization. For products to aid the handicapped, industrial participation is often not available in the middle stages of product development because of limited market size and high risk of marketing failure.

4. Therefore, it is essential to support research and development efforts at all stages of this process, not only at the two end points. Mechanisms should be investigated which would allow government to participate in the support of middle stages of product development to establish clinical and economic feasibility up to the point where industrial participation can be enticed.

A possible resolution to these problems might be the formation of a private-public corporation charged with the development and market introduction of really promising products.

The intellectual resources and perspective of engineering, the physical sciences, and the behavioral sciences need to be integrated more effectively into biomedical research and development relating to the physically handicapped. Many of the devices and procedures that have potential for alleviation of handicapping conditions require the application of sophisticated engineering principles and techniques as well as awareness of the psychological and social factors that enter into their acceptance.

Care of the disabled in the acute phases of illness must not be separated from rehabilitation. The medical team caring for the patient on an emergency basis must be fully aware of the possible long-term consequences of therapeutic measures intended for short-term goals. This awareness sometimes can be achieved by special centers for particular disabilities or chronic conditions (such as spinal cord injury centers or burn centers), provided these centers are located in medical settings with appropriate back-up facilities. These centers can provide an excellent opportunity for combining research and development with patient care.

II. REHABILITATION IN OUR SOCIETY

Medical and Social Framework

The physician trained in traditional medicine is oriented towards the care of patients with acute and often curable diseases.

Rehabilitation is a le.s dramatic form of patient care. It requires less direct physician involvement, and must deal with the realities of permanent impairment. In addition, the newness of rehabilitation medicine as a separate field of specialization means that much of the process is still in the formative stage. These differences have made it difficult to encourage physicians to select this field as their chief mode of practice. Rehabilitation medicine became a formal, board-certified specialty in 1948. Growth during the subsequent 25 years (from 400 to about 1,500 physician specialists) has resulted largely from federal funding through the Rehabilitation Services Administration and its predecessor agencies. Today specialists in rehabilitation medicine represent only 0.44 percent of the 334,000 physicians in the United States, partly because of the low prestig. of this specialty in comparison with other medical specialties.

Experience has demonstrated that physicians can be attracted to the concepts of rehabilitation if the approach is modified to make rehabilitation procedures and principles part of the total care process. Acute and chronic management are blended as "degrees of restoration" so that every patient displays some kind of progress.

A further means of attracting physicians into the practice of rehabilitation is to relieve them of all activities that do not require their specialized skills by developing highly competent groups of allied health professionals. Between 1950 and 1969 these latter fields have grown significantly. There has been a more than threefold increase in the number of physical therapists (from 4,600 to 14,500) and in the number of occupational therapists (from 2,000 to 7,000) and approximately a tenfold increase in speech pathologists and audiologists (from 1,800 to 18,000) and vocational counselors (from 1,500 to 12,000). The engineer's place in the rehabilitation team is still ambiguous and formally exists only in the Veterans Administration and in the Rehabilitation Services Administration Rehabilitation Engineering Centers.

Progress in rehabilitation medicine has been in two directions: (a) a refinement of the rehabilitation process, and (b) a gradual transition from a practice totally devoted to lessening residual disability (i.e., a salvage program) to one of increasing involvement in the subacute and even the acute stages of disease and injury through measures that prevent secondary aggravation of potentially catastrophic situations. A companion of the acute program involvement is a drive to develop means of preventing disabling episodes. To be effective, the emergency and acute care specialists must be acquainted with the rehabilitation potential of catastrophic lesions.

Experience has taught that to lessen or avoid catastrophic physical impairment, close cooperation between the emergency, acute care, and rehabilitation experts is required. In some instances, this is best effected by establishing specialized centers that offer total care devoted to particular types of impairment (i.e., burn centers, spinal cord injury centers, stroke centers, trauma centers, cardiac centers, vision centers, hearing centers, and so on). Specialized centers can also provide an excellent opportunity for combining research and development with patient care.

Demography

There is no way to accurately cite the number of physically handicapped persons in the United States today. While there have been numerous data-collecting studies, inconsistency in the types of impairment included, patterns of classification, and criteria of significance have varied widely. For example, a conservative estimate derived from a study by the Urban Mass Transportation Administration was 13,390,000 handicapped persons, about 6 percent of the United States population. A more realistic estimate would be 10-12 percent of the population. A common finding in all the studies is that there are a significant number of disabled people in the United States and that this group is continually increasing. Today the severely injured are less likely to die, and formerly fatal diseases are often arrested. A study that could serve as a model for other surveys was conducted by the Organization for Social and Technical Innovation, Inc., to assess the field of blindness and services to the blind in 1968.

Organizations and Programs

Society has responded to the needs of the disabled by creating a large number of organizations. Again exact numbers are elusive. The Directory of Organizations Interested in the Handicapped describes 225 organizations in an admittedly incomplete list. Some focus on certain age groups and others on specific diagnoses. There is considerable overlap in functions, many gaps exist, and competition for the same handicapped population is common. Robert Scott,* in his study of the blind, found about 800 agencies and programs in the United States concerned with this one disability group. A similar mosaic of organizations is found in federal agencies and programs. The Office for Handicapped Individuals has identified 103 such organizations, with the same lack of coordination existing.

*Scott, R. A. The Making of Blind Men. New York: Russell Sage Foundation, 1969. 145 pp.

The Policy Picture*

Legislation concerned with rehabilitation began with the National Civilian Vocational Rehabilitation Act of 1920. In the ensuing years rehabilitation emphasis has been almost exclusively on support of handicapped persons with demonstrable vocational potential. In 1954 research provisions were included for the first time. The Rehabilitation Act of 1973 expanded vocational concerns by directing that special attention be given to those with the most severe handicaps. In addition a one-million-dollar grant was awarded for study of the severely handicapped population without vocational potential. This act also redefined the support for the Rehabilitation Research and Training Centers, which were begun in that year. Support and expansion of the Rehabilitation Engineering Research Center concept were also stipulated. These programs were initiated in 1971.

The Rehabilitation Act of 1973 also called for the establishment of the equivalent of study sections with peer review and for a general advisory group. Actions relating to these latter recommendations have been slow in evolving. Undoubtedly this delay results in part from the location of responsibility for rehabilitation science and technology within an organization (Rehabilitation Services Administration) which is primarily oriented to service and which devotes 95 percent of its budget to vocational assistance to the handicapped. Research is further deemphasized by decentralization of the agency into regional offices throughout the country and by the designation of state vocational rehabilitation agencies as final units that make the scientific decisions and fiscal allotments.

In FY 1975 the federal government spent 7 percent of the total budget for health on research and development. Only 0.8 percent of the federal research budget was earmarked for rehabilitation research. This seems a disproportionately low figure for an area of such magnitude both in numbers of afflicted and in total economic burden.

New laws and public statements by rehabilitation agency officials are raising the expectations of the physically handicapped beyond that of pure vocational service. Expectations include assistance in education, transportation, use of public accommodations, recreation, health care, and access to the election ballot. The expectations from science and technology by the handicapped population vary widely, depending on the individual's personal needs. Presumably consumer representation on the agency's policymaking boards will expand their appreciation of the opportunities, as well as the limitations, offered by science and technology.

*A series of supporting papers on economic, social, public policy, and consumer issues relating to rehabilitation of the physically handicapped are included in Volume 2 of the full version of this report. These papers are listed in the contents. The findings and recommendations in these papers are those of the authors.

Economics of Rehabilitation

Statistics on gross expenditures related to health care are available, but identification of that portion related to rehabilitation is not possible at this time. A major limitation is the failure of agencies and programs to differentiate between preventive measures, acute care, and rehabilitation. A rough estimate of the magnitude of the expenditures can be made from isolated studies. For example, in 1967 national expenditures related to blindness totaled almost $470 million, of which 85 percent was from federal/state sources.* Extracting the cost of illness relating to the neurological and connective tissue systems from a Social Security Administration study on the cost of illness,** expenditures for physical handicaps (which fall primarily in these two categories) were $19,899,000,000 in 1972. The significance of such numbers, however, is dependent on the number of persons served, their level of initial impairment, and the outcome of their rehabilitation. These correlations tend to be treated as cost-benefit assessments. However, such analysis of rehabilitation cannot be valid until all the influential factors have been satisfactorily identified and defined.

*Organization for Social and Technical Innovation, Inc. Blindness and Services to the Blind in the United States. A Report to the Subcommittee on Rehabilitation, National Institute of Neurological Diseases and Blindness. Cambridge, Mass.: OSTI Press, 1971.

**Cooper, B. S., and D. P. Rice. The Economic Cost of Illness Revisited, p. 31, Table 7. Social Security Administration. DHEW Publ. No. (SSA) 76-11703. Washington, D.C.: U.S. Department of Health, Education, and Welfare, February 1976. 16 pp. (21-36)

III. STATE OF THE ART: SCIENCE AND TECHNOLOGY AND THEIR APPLICATION

Research and Development

Following definition of clinical need, the application of science and technology to improve the handicapped person's performance capability involves four critical stages: research, development, evaluation, and marketing.

Basic research is commonly defined as the search for new knowledge per se with the investigator following whatever track is presented by the theory or data. Applied research is directed toward solving an identified problem. When one seeks to answer the needs of the handicapped, the division becomes blurred. To accomplish the applied objective, basic questions must be answered. For example: What is the capacity of the skin and brain to acquire and interpret multidimensional, dynamic information presented by vibratory or electrical stimulation? This type of research seeks to discover the ways in which normal functions can be expanded to substitute for other losses. The ability to answer this question depends on the qualities of the basic scientist and his techniques. Yet there is a more basic goal. The answers will be employed by applied researchers to give "vision" to the blind and to create position sense and object identification capability in the amputee and paralytic.

In the course of seeking this basic knowledge, devices such as a prototype prosthesis may be used. Extra care must be taken that such testing will not be construed as clinical evaluation. Such a misconception could readily lead to rejection, for the work would be erroneously judged on its applicability rather than on the new knowledge being provided.

Laboratory models of products for the handicapped obtained through applied research are sufficient to confirm the feasibility of the concept. Some projects also provide funds for clinical trial of a limited number of copies of the prototype device. However, even these latter devices must undergo an extensive developmental process of redesign and evaluation to be transformed into a manufacturable product that meets all the functional and technical requirements and that is also reliable and safe for human application. The final cost of the process of development is usually tenfold and may reach one hundred times that involved in the original research. Agencies supporting research rarely are familiar with the nature and cost of the developmental process. In contrast the Department of Defense, well aware of the need for development, maintains in-house organizations for just this purpose. The lack of comparable service in the Rehabilitation Services Administration is a critical gap in the process of technological advances reaching handicapped persons. Each product has a relatively small potential market, the eventual "consumers" generally have limited

finances, and the purchase generally depends on the physician's prescriptions. To overcome these limitations it has been suggested that a private-public corporation be formed and charged with the responsibilities for development and market introduction of promising rehabilitation products and devices.

The evaluation process itself should be conducted at two levels. The developer is most likely to detect the cause and seek the remedy for performance imperfections, while independent parties are the best judges of whether the device can be used in the target population. Their experience will also test the accuracy of device definition and the training procedure for its use.

Blindness and Low Vision

Vision is the prime channel of communication between the individual and the environment for both utilitarian and aesthetic purposes. The basic concerns in technological replacement of lost vision are provision of practical access to the printed page and unhampered mobility within the environment. Other needs such as sign reading, gesture observation, and scenic and artistic enjoyment are yet to be considered.

The problems are complex because the other sensory systems available as substitutes are so much less versatile. The ear has only 40,000 neurons extending into the brain, in contrast to the 1,000,000 nerve fibers reaching from the eye to the brain. Similarly the visual television capability is often 525 lines of resolution while the fingertip can handle only 6. Thus the challenge is very complex. The spectrum of visual impairment related to technological needs divides readily into two groups: the totally blind who need a visual prosthesis that will translate ordinary printed material into natural speech and the low-vision people who need enhancement of their limited but vital capability.

Several nonvisual reading aids for the totally blind exist. Although technically complex, they are now at the feasibility stage. A direct translation unit converts the output of a photocell into either a one-dimensional auditory display or a two-dimensional tactile display. While recent developments have made feasible the volume production of small portable units at relatively low cost, the performance still is crude, resulting in considerable information loss. It does permit independent textbook reading, a service enthusiastically received by students.

Work continues toward developing machines that will recognize individual characters and appropriately translate them into either auditory or tactile representation. Optical character recognition systems have received considerable commercial development in recent years. The current systems can only read the 10 digits and a few other symbols in a fixed-type format. Companion to this is a computer-coupled multi-million-dollar system that reads multifont typewritten characters rapidly and accurately.

An intermediate system that allows spelled speech output utilizes electronic logic to recognize printed letters. Two laboratories are currently working to overcome existing difficulties in this system. Recent technical advances also have demonstrated the feasibility of a talking calculator to provide speech synthesis from the written word. Costly computer pattern recognition techniques combined with speech permit direct translation of printed English into audible speech. While still economically prohibitive they represent a dramatic technological advance.

Conveying sufficient information about a blind person's surroundings to make navigation safe is an extremely difficult challenge. The input is not well constrained, and definition of pertinent information is difficult. To complicate matters further, an individual's perceptual concepts may change radically with the onset of blindness or may be distorted in the congenitally blind. All agree that the currently available mobility aid devices still restrict the blind person's freedom. While various types of direct-translation systems are constantly reconsidered the probe detectors continue to seem more practical in spite of their obvious limitations. Ultrasonic and optical-triangulation devices such as the laser cane are also being developed. The laser cane preserves the advantages of the long cane while adding tactile and audible signals to give earlier warning of obstacles such as stairs, and to identify overhanging objects. Another ultrasonic device is an energy mechanism, carried on the chest like a small camera, that explores the area above and ahead where the blind person is probing with a cane. The display is simple and decisions are made in real time. So far no device attempts automatic recognition of the features in the visual field. With further refinement some still experimental mobility aids could be very useful as supplements to the long cane or guide dog. Some devices may eventually provide useful mental constructs of the three-dimensional world to the congenitally blind. Attempts to excite the cortex electrically in a way that will produce a recognizable pattern of the object "visualized" have been rather disappointing. While vague but repeatable geometric information is obtained by some persons, nothing has occurred in others. There are also indications that neural damage can result from the quite large and frequently repeated electrical currents that must be used.

Direct electrical stimulation to the brain is not currently a promising approach to the rehabilitation of the visually handicapped.

Low vision aids are needed by people whose vision, even with maximum eyeglass correction, is not adequate for the performance of such common tasks as reading or sewing. The functional significance of such visual limitation is relative to the individual's occupational and recreational needs (legal blindness starts at 20/200, which is 1/10 of normal acuity). Unusually strong reading lenses are the common vision aids used by persons with functional limitation of vision. Some are fitted as eyeglasses; others are held in the hand. Telescopic aids serve a small percentage of the low vision population. Closed-circuit television is much more effective. It provides a means of electronically manipulating magnification and contrast in ways that make reading and writing much easier than do optical aids. These units still are too large to be portable and are expensive.

Prescription of proper aids is currently limited by the unfamiliarity of the average practioner with their relative value and by the lack of teaching time to instruct the patient in the new skill. In treating the population with low vision, the greatest need is proper distribution of simple, inexpensive, off-the-shelf items that industry knows already how to make, rather than expensive breakthroughs in technology.

Hearing and Speech

Communicative disorders can generally be defined as impairment of the abilities to hear and understand speech and to produce normal-sounding and understandable speech. Disorders of the ear, the vocal tract and various brain structures can arise from a variety of causes, including genetic and birth defects, infection, or trauma; these disorders cause impairments of hearing, language, articulation, and voice.

Impairments of hearing and voice result primarily from peripheral disturbances, language disorders usually arise from central nervous system disturbances, and disorders of articulation from both. Disorders of hearing, voice, language and articulation may be combined, especially in children.

Scientific and technological needs for the hearing-impaired relate to a means of detecting deafness as well as measures to overcome the limitation.

Traditionally, deafness has been defined according to a person's ability to hear pure tones at discrete frequencies. Realization that speech is far more complex than this has lead to the development of speech audiometry. Behavioral and electrophysiological audiometry for children has progressed significantly. By combining operant conditioning with audiometry, diagnosis of hearing disorders is being accomplished in much younger children. This permits the application of more appropriate remedial measures to prevent the secondary effects of hearing loss. Screening for hearing impairment in children should be expanded.

Impairment of hearing relates to two distinctively different clinical groups: those who are hard of hearing and need an aid, and those who are totally deaf and require translation of speech into another sensory modality.

The hearing aids of today are audio-amplifiers whose basic characteristics have not truly changed since they were introduced 40 years ago. Advances have been in miniaturization, lengthened battery life, reduction of harmonic distortion, use of amplitude compression, and improved versatility. The advantages of signal processing have not been introduced. To permit specification of functional design goals, the field needs basic knowledge of the way speech is perceived by those with hearing impairment.

In summary, the advances in hearing aid design have been responses to commercial pressures rather than a scientific analysis of the disorder and technological potential for replacing the deficit. The need for improved

aids will increase since the percentage of persons over 65 years of age in the population is increasing.

Past experience with high-power hearing aids improved the lip-reading scores of the profoundly deaf person approximately 10 percent. Concerns lie with both better "hearing" and improved speech training. Devices that transfer speech into visual or tactile displays are expected to be more effective. Limited but important gains in speech reception have been made. Assistance in speech training for youngsters who are deaf at an early age appears promising, but scientific evidence of gain is still lacking. The original bulky and slow devices have been replaced with wearable units. One aid (Upton-Aid) visually displays "features" of speech in such a way that it also allows the eye to be used for other activities. Another (Saunders-Aid) provides an electrocutaneous display of speech. It is important that these devices be moved from the prototype stage into well-developed devices that can be given adequate clinical trial.

Another direction of research is direct electrical stimulation of the auditory nervous system via implanted electrodes. To date they provide no better speech reception than a simple vibrator. The implant approach requires surgery with its attendant risks and is very costly; it does not seem as promising as other approaches in the near future.

Language formulation is a cognitive function with progress dependent on advances in speech therapy. Impairment of speech and language affect two major populations, one composed of children with an isolated language lag (compared to the development of general intelligence), the other composed of adults with acquired communication disorders from brain damage. A major need for research in these areas is in development of better ways for assessment.

Poorly articulated speech may be associated with cleft lip, cleft palate or other defects, neurological disorders, or emotional and psychosocial factors. Often, in children, the cause is not known. The combined efforts of surgeons, speech scientists and speech pathologists, and dental prosthetists can often restore essentially normal speech and normal appearance to the person with cleft lip and cleft palate. Articulation problems due to neurological defects are difficult to correct; research on normal speech production, however, may lead to advances in this area.

Aside from psychogenic causes, disorders of voice arise mainly from laryngeal disease or trauma. Surgical repair of the larynx maintains the capability of voicing, but speech quality is dependent on the combined team efforts similar to that accomplished by the cleft palate units.

Individuals with complete loss of the larynx have a great need for an adequate substitutive device. Even though in a laborious fashion many can learn esophageal speech (swallowing air and "burping" in a controlled manner to simulate voice), 25 to 40 percent of the patients cannot. The existing artificial larynxes (electronic or pneumatic) make speech immediately available to patients; however, the quality is poor, the power low, and the pitch

control absent. Technology exists to produce pocket-sized speech synthesizers which may fill the need of a person made mute by disease or trauma. Otherwise normal persons who have an ineffective or unpleasant voice are significantly handicapped in their social interactions and vocational options. Research and development of devices for production of voice should be strongly supported.

Manipulation and Locomotion

The numerous disabilities that limit a person's capacity to manipulate or move in his environment may be grouped in three broad categories: deformities (including amputation), paralysis, and skeletal joint destruction.

Amputation creates a profound disability, since the losses are skeletal, muscular, and sensory. Prosthetic research has paralleled technological potential. Artificial limb segments are mechanically acceptable but still need durable covers with a more natural texture.

In the lower limb the key to walking capability is knee control, which can be provided by a variety of hydraulic, pneumatic, and mechanical passive units. However, timely activation of the stance control and initiation of swing depend on the physical ability of the patient to provide the appropriate body motion. The age of the patient and the number of limbs involved are very significant in prosthetic effectiveness. Controls that permit running, climbing, and so on for the young amputee who has lost his knee are not available. Amputations at the hip and higher present far more severe restraints. Thus, development of active control and appropriate feedback is still much needed for the lower limb amputee.

For the upper limb, versatility is a critical need, hence tremendous effort is being exerted to replace mechanical cable controls with electromyographic signals. Selective grasp has been effectively provided for the person with a below-elbow amputation, although he still must rely on mechanical adjustment or postural substitution for wrist and forearm positioning.

Prostheses for above-elbow amputees are difficult to provide because two areas (elbow and hand) require selective posturing and fewer control sites are available. There are several experimental approaches toward solving this problem using electromyographic signals and the natural synergies of the shoulder muscles, which tend to combine with key elbow and hand actions during selective tasks.

For more selective control, another research approach uses the neuroelectric signal detected by electrodes placed directly on peripheral nerves.

Sensory feedback research is still in the early experimental stage. Transduction of motion, position, pressure, and temperature in the artificial limb is relatively straightforward but presenting the feedback information to the nervous system and brain has proved to be very difficult.

Various types of skin stimulation, coding of direct neural stimulation, and long-term biocompatibility all need further research.

Another area of concern in limb prosthetics is direct skeletal attachment of the prosthesis to avoid the insecurity that soft tissues impose between socket and stump. While materials compatible with bone are readily available, finding tolerable means of penetrating the skin has proved to be very difficult. Motion created at this interface continues to break the physiological seal, leading to eventual rejection of the foreign item.

Orthoses commonly are employed in the management of deformities of the intact limb; their purposes are to assist with correction of contractures, and to compensate for the instability and malalignment. All such devices provide the single function of static support. Considerable progress in mechanical effectiveness and cosmesis has accompanied the introduction of plastic, particularly the vacuum-formed polypropylene.

Muscles provide two equally important functions: creation of motion and its selective restraint when joint stability is desired. In the management of paralysis, today's orthotic substitutes primarily serve as stabilizers, restricting motion with locked or limited arc joints. Orthotic production of motion in flaccid upper limbs is accomplished with springs and elastic bands, but for the lower limb these forces are too light to be effective, except to pick up a drop foot. Electronic and carbon dioxide "motors" also have been designed but they suffer the same limitations as prosthetics: difficulty in finding sources of remote control and lack of sensory feedback in anesthetic limbs.

A programmed, externally powered orthotic system has been designed to provide artificial locomotion. However, the lack of sensory feedback and the need for very massive power packets preclude practical use.

Persons with upper motor neuron lesions (stroke, brain traumas, cerebral palsy) have intact peripheral neuromusculature but lack normal central control. For these patients motion can be effected through functional electrical stimulation. A unit already commercially available activates the peroneal nerve to pick up a drop foot. This system incorporates a heel switch, a radio transmitter, and an indwelling electrode around the nerve. Extensive clinical trial in a number of centers has verified its effectiveness. The same approach has been applied occasionally to the femoral and gluteal nerves to control the knee or hip. Recently multichannel surface stimulation has been introduced to provide simultaneous hip, knee, and ankle control. This approach is still experimental since coordination of stimulus timing to the patient's gait pattern is lacking. In the upper limb, functional electrical stimulation has been limited to re-education and contracture correction of a single muscle.

Arthritic deterioration of joints has been a major cause of pain and disability for centuries. Orthopedic management of patients with these disabilities was revolutionized by the introduction of total hip replacement. Artificial joints are available now for most areas of the body either as commercial products or as experimental models. Clinical success is greatest

in the hip because its normal anatomy (ball and socket) can be accurately reproduced with mass production techniques, but for replacement of joints with more complex anatomy this has not been possible. Loosening of the devices within the bone because of concentration of force and failure to provide some of the functions available in a normal anatomy are limitations that make surgeons justifiably reluctant to use these devices until a patient is severely disabled. The consequences of such delay are loss of soft tissue mobility and muscle atrophy sufficient to limit the potential of the artificial joint permanently.

Basic Neuroscience and Rehabilitation

The most compelling problems in human rehabilitation are those requiring a recoupling of brain function to the peripheral motor and/or sensory organs. Ways to stimulate central nervous system regeneration, comparable to its occurrence in the peripheral tissues, are being explored through basic neurobiological research. Studies of nerve tissues in culture are identifying the requirements for growth and duplication of nerve cells. Neuronal "recognition" studies seek to define the process employed by growing axones to locate their appropriate area of "cell interaction" in mammalian brain development. Clinical neuroscience studies relate to pathophysiological and anatomical changes associated with spinal cord injury. The mechanism of neural plasticity also is being explored to learn how functions lost through injuries can be replaced by remaining intact areas of the brain.

It is evident that basic research in the neurosciences is relevant to the entire spectrum of treatment and rehabilitation of physical disability, from the acute measures taken for the initial illness or injury to the rehabilitative process which follows.

VOLUME 1

CONTENTS

PREFACE v

I. FINDINGS AND RECOMMENDATIONS 1

II. REHABILITATION IN OUR SOCIETY 5

The Medical and Social Framework 5
Rehabilitation Medicine 6

Demography 8
Definitions 8
National Demographic Data 10
Sensory (Vision and Hearing) Deficits 13
Vision 13
Hearing 13
Motor (Locomotion and Manipulation) Deficits 14

Organizations and Programs 14

Manpower 16

The Policy Picture 17

The Economics of Rehabilitation, Including Research and Development 20
Cost-Benefit Studies 20
Veterans Administration 21
Rehabilitation Services Administration 22

III. STATE OF THE ART: SCIENCE AND TECHNOLOGY AND THEIR APPLICATION 26

Research and Development 26
Basic versus Applied Research 26
Device Development and Evaluation 28
Device Availability to Users 29

Blindness and Low Vision 31
The Problem and Population 32
Costs of Visual Impairment 32
Aids for Complete or Nearly Complete Blindness 32
Non-Visual Reading Aids 32
Mobility Aids 34
Direct Coupling to the Nervous System 35
Low-Vision Aids 36
Conclusion 37

Hearing and Speech 38
Impairments of Hearing 39
Language 41
Articulation 41
Voice 42
Conclusion 42

Manipulation and Locomotion 43
Deformity 43
The Amputated Limb 43
The Intact Limb 45
Paralysis 45
Skeletal Joint Destruction 46
Conclusion 47

Basic Neuroscience: Regeneration and/or Recovery of Function of the Nervous System 48

REFERENCES CITED IN TEXT 50

GENERAL REFERENCES 55

APPENDIX--Work of the Committee 59

VOLUME 2

CONTENTS

The Limits of Cost-Benefit Analysis as a Guide to Priority-Setting in Rehabilitation. John H. Noble, Jr. 1

- The Rehabilitation Program 2
- The Cost-Benefit Model 3
- Data and Assumptions 4
- Sensitivity of the Model 15
- Implications and Recommendations 23
- References and Notes 29

Public Policy Towards Disability--The Numbers, The Programs, and Some Economic Problems. Monroe Berkowitz 34

- Introduction 36
- Definition and Concepts 36
- Counting the Numbers of Disabled 39
- Census Data 40
- Age and Disability 40
- Age at Onset of Disability 41
- Epidemiological Factors and Disability 42
- Problems in Counting the Disabled 43
- The Workers' Disability Income System - An Introduction 44
- Income Restoration 45
- Risk Aversion 46
- Status 47
- Social Insurance 48
- Income Support 50
- Indemnity Payments 50
- Overlapping Categories 51
- Other Programs for the Disabled 51
- The Workers' Disability Income System - Summary and Conclusions 54
- Evaluation 54
- Efficiency 55
- Equity 55
- Effectiveness and Adequacy 56
- Some Evaluation Tools 56
- Program Evaluation and the Consumer 57
- Benefit-Cost Analysis and Social Investment 57
- Some Problems in the Application of Benefit-Cost Analysis 58
- Political Decision-Making and Benefit-Cost Analysis 59

Benefit and Costs of the Federal-State Vocational Rehabilitation Program 59

- Benefits 59

Costs 60
Federal-State Vocational Rehabilitation Program as a Social Investment 60
Conclusions 60
Rehabilitation Trends 62
Public Policy Choices 62
References 64

Social Issues in Rehabilitation. Robert Morris 67

Absence of Comprehensive Aggregate Data - Increases in Prevalence of Disability 68
Neglect of Post-Rehabilitation Situations in Severe Disability 7[illegible]
Changing Family Capacities 71
Distorting Effects of Severe Disability on Health and Welfare Systems 72
Other Social Dimensions 75
Social Aspects of Short-Term Rehabilitation 76
Suggested Steps 76
References 78

Public Expectations. Albert T. Pimentel 79

Introduction 80
Legislative History 81
Vocational Rehabilitation 81
Education of the Handicapped 82
Other Federal Commitments 84
Role of Consumers 85
Summary of Public Expectations 85
Bibliography 86

Consumer Perspectives. Albert T. Pimentel 87
Additional Reading 93

Critical Issues Facing the Health Care System. Charles C. Edwards 94

Rational Change in the Health Care System 96
Sounding Board -- Form and Function in the Federal Health Effort 101